

# The ROPAC registry: a multicentre collaboration on pregnancy outcomes in women with heart disease

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**This editorial refers to ‘Outcome of pregnancy in patients with structural or ischaemic heart disease: results of a registry of the European Society of Cardiology’<sup>†</sup>, by J.W. Roos-Hesselink et al., on page 657**

The haemodynamic changes of pregnancy can have a negative impact on maternal cardiac health, especially in women with pre-existing cardiac disease. In the most recent Confidential Inquiries into Maternal Mortality in the United Kingdom, heart disease was found to be the most common indirect cause of maternal death during pregnancy.<sup>1</sup> Pregnancy counselling and management for women with heart disease is being increasingly recognized as an important aspect of their overall cardiac care. With increasing awareness, there has been a growing body of research focused on pregnancy outcomes and risk stratification. There have also been new initiatives to improve clinical care, such as the 2011 European Society of Cardiology (ESC) guidelines on the management of cardiovascular disease during pregnancy.<sup>2</sup> While our current understanding of pregnancy risk assessment and management has improved over the past 20 years, many questions can only be answered by collaborative efforts.

Roos-Hesselink and colleagues have now presented the first report of their multicentre, multinational Registry On Pregnancy and Cardiac disease (ROPAC) registry, supported by the ESC.<sup>3</sup> The study is important because it provides a global perspective on pregnancy in women with heart disease. It included 1321 pregnancies in women from 28 countries, the majority of which were developed countries (86%) in Europe and North America. Most women from developed countries had underlying congenital heart disease (74%). In contrast, valvular heart disease was the predominant underlying cardiac condition (72%) in pregnancies reported from women in developing countries where rheumatic heart disease remains endemic. The study reports high rates of adverse maternal cardiac events during pregnancy including increased risk of maternal deaths. Hospital admission for cardiac reasons complicated 15% of

all pregnancies, primarily for treatment of heart failure. Similarly high event rates of adverse maternal cardiac events have been reported by other groups (Figure 1).<sup>4,5</sup> Collectively, these studies highlight the need to identify women at highest risk and to develop care models to improve outcomes. Because maternal deaths at any one centre are relative rare, large multicentre registries such as this are necessary to study mortality outcomes. Although rare, maternal mortality (13/1321 pregnancies, 7 due to heart failure, 3 due to thrombo-embolic events, and 3 due to non-cardiac-related sepsis) was much more likely to occur in women with heart disease compared with the general population. While there are a number of risk scores for predicting adverse pregnancy outcomes in women with heart disease, this study externally validated the model proposed by the British Working Group, demonstrating its utility in predicting maternal mortality, the occurrence of heart failure, and fetal death.<sup>2,6</sup>

Cardiac disease in pregnant women will probably be increasingly encountered in medical practice. With advances in cardiac surgery and improved childhood survival, there is a growing population of young women of childbearing age with congenital heart disease.<sup>7,8</sup> Most of these women, particularly those with lesions of moderate or great complexity, have residua or sequelae that increase their risk of cardiovascular complications during pregnancy. Rheumatic heart disease, rare in developed countries, remains a major health problem in developing and underdeveloped countries. Women with rheumatic valve lesions such as mitral stenosis tolerate pregnancy poorly.<sup>9</sup> The prevalence of ischaemic heart disease complicating pregnancies is increasing,<sup>1,10,11</sup> perhaps related to trends in western societies of having children later in life and associated higher rates of cardiovascular risk factors in this older cohort. Further increases may occur with increasing assisted fertilization in older women. With this growing and evolving population, ongoing education of health care providers and patients is important.

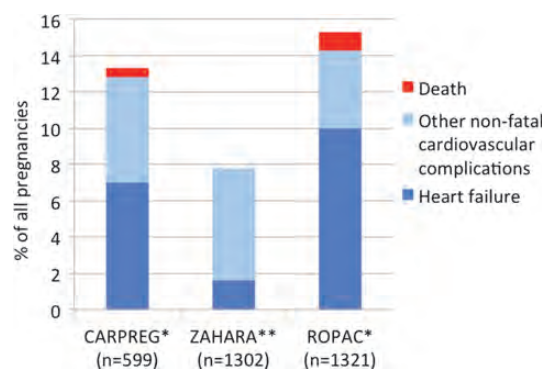
Pre-conception counselling allows women to make informed pregnancy decisions, and risk stratification tools can be helpful to

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**Figure 1** Risk of heart failure, other non-fatal adverse cardiovascular events, and maternal death in three large multicentre studies of pregnancy outcomes in women with heart disease. \*The CARPREG study and the ROPAC registry include women with congenital and acquired heart disease. \*\*The ZAHARA study included only women with congenital heart disease.

predict pregnancy risk. A number of risk stratification tools have been proposed to identify those women at highest risk.<sup>4–6,12</sup> For some cardiac lesions, there is very little risk of adverse cardiac events during pregnancy, no special precautions are required during pregnancy, and women need nothing more than reassurance. In other cases, pregnancy poses a prohibitive risk and women need to be educated about the need to avoid pregnancy and about safe contraception options. Unfortunately, a number of groups have reported that women with heart disease often have inaccurate knowledge of pregnancy risk.<sup>13,14</sup> Once pregnant, women identified as intermediate or high risk should receive coordinated care, with input from a cardiologist with expertise in pregnancy and heart disease, a high-risk obstetrician, and an obstetrical anaesthetist. To date, few studies have addressed delivery of care or quality of care in this high-risk population.

The ROPAC registry is likely to have many roles. As the registry increases in size, rare cardiac conditions or outcomes (such as maternal, fetal, or neonatal mortality) can be studied in more detail. The registry data can be used for validating and refining existing risk stratification scoring models or identifying novel risk markers derived from smaller mechanistic studies. The registry data can help to determine and compare regional treatment strategies and outcomes. Other parameters, such as healthcare costs, could be studied. The ROPAC registry is an important initiative that will help to improve the care of pregnant women with heart disease.

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